Sense FOCUS ON 1986



The National Deaf-Blind and Rubella Association Annual Review

• MEETING THE NEED

OTHE NEXT STEPS



This year has been one of growth and also of planning. We have continued to expand and develop our services; vet we have also taken the time to reflect on how Sense can adapt to face the challenges of the year ahead. Every area of our work has seen expansion. In our work with deaf-blind young children, with schoolchildren, with young adults, we are providing more services to more people. We have continued our work to prevent deaf-blindness, through the Rubella Awareness Campaign. Our information and campaigning on all aspects of deaf-blindness have increased. We have offered more support to families, in all parts of the country. Now we are looking ahead, setting our priorities for the future. Throughout the year, staff and committee members have been meeting, evaluating our past achievements and discussing what are the crucial next steps forward. We are resolved now to

• Extend the Family Advisory Service, to provide a fuller service to the families of young children;

 Develop an Education Service and play a central part in the growth of new educational opportunities for deaf-blind children; and

• Encourage suitable longterm care facilities for deafblind adults.

Sense's work depends upon the dedication of many people; the staff, the volunteers who help us in all parts of our work, the committee members who support and advise us, and the many many people who give the money to enable everything to happen. To them all I give grateful

Jessica Hills Chairman

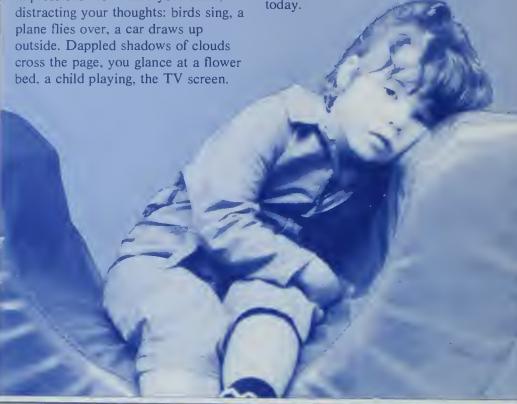
LUCY'S WORLD

Lucy is deaf and blind. What can she expect from life? How can she begin to understand her world without two vital senses?

WHAT CAN IT BE LIKE?

Look about yourself. You are in a room, or perhaps outside, sitting in your garden. A thousand sense impressions crowd into your mind, plane flies over, a car draws up outside. Dappled shadows of clouds bed, a child playing, the TV screen.

But suppose you couldn't see or hear? How could you begin to understand anything beyond your reach or touch? Ninety-five per cent of all the information that comes to our brains comes from sight and hearing. To be without senses is to enter a scarcely imaginable world, a frightening world - yet there are about 10,000 deaf-blind people in Britain



•SENSE -THE NATIONAL DEAF-BLIND AND **RUBELLA ASSOCIATION**

Dr. G.B. Simon, MB ChB DPM FRCPsych

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Chairman Jessica Hills, MBE

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SENSE

Sense exists because a child who is born deaf blind is going to need help to reveal her full potential.

Sense exists because the family will need support in coming to terms with their disabled child, and in learning how to communicate with her.

Sense was founded by parents for parents, and from their mutual support comes comfort and sharing.

GROWING UP

As Lucy grows up Sense will be behind her, trying to ensure that she will get the education best suited to her needs, provided by highly trained and specialised teachers. Later, as a young adult she may be found a place in a specialist centre where her skills will be developed further and she will be led towards as much independence as possible. The need for more money, more resources and more public awareness of the extent of the problems of deaf-blind people is enormous. Sense is doing what it can.



Last year Charles lost a little more of his sight. Born deaf, he has Usher Syndrome, which eauses a progressive loss of vision in 3 – 6% of the eongenitally deaf population. Sense's Usher Syndrome Project promotes awareness of this eondition, and eooperates in research. Through eounselling and support, people with Usher Syndrome ean be helped to adjust to their loss.



V Last year David moved

Manor House for deaf blind

young adults he has learnt to

look after himself, to cook and clean, and to shop for himself

Now he has moved into a Sen e

group home down the road, to

independence skills into effect

put his newly learnt

house. Over the years at Sen e'

Last year Jamie's parents were among 200 families who saw Sense's Family Advisory Service. At the Ealing Family Centre, they explored ways of building up communication with Jamie, and learnt new ideas for helping him to develop. The Advisory Service Team will provide assessment, support and guidance throughout the vital early years.



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● HOW MANY PEOPLE NEED OUR HELP?

• Last year our Family Advisory Service was assisting more than 200 families with deaf-blind children under the age of five. We think there are many more, unknown to us.

• Last year we know that 100 sehool-age children were being educated in specialist units. At least 500 more are still not receiving all the specialist teaching their sensory handicap requires.

• Last year many deaf-blind people, produced by the rubella epidemie twenty years ago, are still living in Mental Handicap Hospitals.

• Last year we helped more than a hundred people with Usher Syndrome, where deafness from birth is followed by a gradual loss of sight in adulthood. We know of over 300 people with Usher Syndrome.

• Last year many families joined local Sense Branches and found themselves among understanding friends with similar problems.
For some it was the first time they had met anyone else with a deaf-blind child.
Now they can share ideas, find comforting support and shed their loneliness.
Sense helps and encourages families to form local groups.

• Last year Sense in Scotland completed a preliminary survey of the number of deaf-blind people in Scotland, the first ever undertaken. The figures showed about 140 deaf blind people under the age of 50. Sense is just starting to make its services available to them

* NATIONWIDE

OHOLIDAYS

Sense has organised twelve holidays for over 100 children this year, more than ever before. Yet the demand for places grows and outstrips our resources. Parents, however patient, can be worn down by the demands of a multi-handicapped child. Often their only break from pressure is when Sense takes their child on holiday. And the children love it! Our holidays are carefully graded to suit the ages and abilities of the children and young adults taking part. The younger ones enjoy the beaches and the hills, while the young able adults are offered more challenging activities to stretch their abilities. Severely handicapped young adults are catered for at Edgbaston, where there is a pool, a gym and a sports field.

Each holiday is supervised by professional staff and volunteers with at least one carer per child. Sense tries to ensure that no family is unable to take up a holiday offer because of lack of means.



•INTERNATIONAL LINKS

Our 400 members abroad share their news and ideas with us through 'Talking Sense' and our braille newsletter.

Last year, Sense delegates spoke at the European Deaf-Blind Conference at Bruges, while leading North American and Scandinavian teachers came here to talk to us.

We share in and help organise Mobility International Holidays, making friends with our neighbours from many countries. Deaf-blind people; their needs are so great, yet their numbers relatively few. Services come to those who shout loudest, and for too long there has been little shouting on behalf of deaf-blind people and their families. Now Sense represents their interests, and campaigns both nationally and locally.

Nationally, we have worked for better social security benefits for deafblind people. Hundreds of Sense members lobbied their MPs about extending mobility allowance, and we



Taking our message to No. 10

are beginning to see the success of this. Along with other disability organisations, we have called for the introduction of a Comprehensive Disability Income Scheme, to offer a decent benefits system for all disabled people.

We have helped many individual deafblind people and their families in their claims for Mobility Allowance, Invalid Care Allowance and other benefits, and we have fought and won some crucial test cases on the rights of deafblind people to a decent income.

Sense has also had its input on a range of the major issues affecting deaf-blind people — on Child Care Law, on hospital closures, on parking concessions for disabled people, and many others. Sense was in at the beginning of the drafting of the new Disabled Persons Act which, if implemented, could dramatically improve services for all disabled people.

•TALKING SENSE

Talking Sense is our illustrated quarterly newsletter. It contains a range of articles, news reports, notices and letters of interest to all concerned with deaf-blind people.

Thoughtful professional features by educationalists and health workers are complemented by human interest stories of the activities of schools and residential units.

In Members' News, parents write and share their sorrows and successes.

Talking Sense offers its columns to all who are interested in the welfare of deaf-blind adults and children.

•BRAILLE NEWSLETTER

Sense's new development officer, deaf-blind himself, now edits and produces our well-established brailled digest of Sense's quarterly newsletter 'Talking Sense'.

We are extending our braille production capacity so that we can increase our services to braille readers in Britain and abroad.





On Education, the first steps towards a national strategy for Deaf-Blind Education are being taken. After countless meetings and representations from Sense, the Department of Education and Science are now seeking to find out just how many deaf-blind children there are, and what

education service they are receiving. The prospect of a full-time course for teachers is nearer than ever, and the applications to attend Sense's short courses have remained high.

Locally Sense supports individual families. Information about local or national services can help parents find the right placement for their child. We offer advice on who to turn to, and how to secure appropriate help. If the authorities seem unwilling to help, Sense can seek to persuade them. Sense's Families Fund can provide small grants to help buy special items of equipment.

USING THE MEDIA

Sense uses any means to get the message across about the need of deaf-blind people. Last year we encouraged articles in local and national newspapers, featured in three TV documentaries, and built up contacts with local radio and magazines. Jane Asher's TV appeal brought in welcome funds and public interest.



INFORMATION

"Dear Sir.

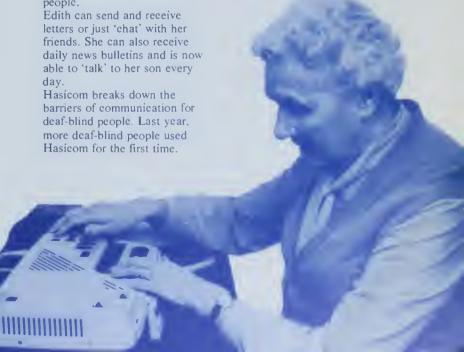
I am doing a project at my school on deaf-blind children and I was hoping that . . . Every day the mail includes requests for information, from sehoolchildren, parents, teachers, social workers, psychologists. Questions range from "what is rubella?" to "where ean my child go when he leaves school?" To answer the needs, Sense provides a wide range of factsheets, newsletters. information packs and videos. and has access to specialist advisers on several topies.

• SENSE'S LIAISON OFFICER...

"A foster parent rang me up seeking help and advice. She wanted her child to be assessed under the 1981 Education Act, which says that once a child's needs are identified suitable education must be given. This child was born in one county but fostered in another thus the responsibility was split between two authorities, and it was complicated. I talked to the foster parent and we started trying to sort out her problem."

• HASICOM

Hasicom is the Hearing and Sight Impaired Communication Programme; it is Edith's chief link with the outside world. By connecting her braille terminal to a central computer through a telephone link she connects into an electronic mail system used by thousands of people.



• FAMILY ADVISORY SERVICE •

CATION
and child,
is taking place
The Family Advisory Service supports

The Family Advisory Service supports families and others working with young deaf-blind children. From the Ealing Family Centre, the Newcastle Resource Centre and – soon – the Edgbaston Family Centre, Sense staff offer developmental assessments, family advice, parent workshops and many other services.

David Brown is one of Sense's Advisory Teachers. Every week is different for him; here is one of them:

MONDAY

I went to the Neo-Natal Unit of a large hospital this morning, to see a 3-month old little girl with Congenital Rubella Syndrome and her parents. I have been visiting weekly since she was 3 weeks old, though that will reduce a bit now. We are all looking forward to the baby's discharge from hospital, so her family can really get to know her. Today's visit was mostly to deal with her new hearing aids.

After lunch I visited a family to meet a mother and her twins, aged six, one of whom is severely multiply handicapped. As it was my first visit, we just began the process of making friends and fixed a date for the whole family to come to the Ealing Family Centre to meet our team.

TUESDAY

To a school for children with Severe Learning Difficulties, to see a 6-year-old deaf-blind child. I worked with the staff there on how to use ultra-violet light to stimulate his remaining vision, how to overcome some feeding problems, and how to use manual signs for communication.

WEDNESDAY

A morning for planning and reportwriting, then a family arrived to spend a few days at the Family Centre. The family will meet lots of professionals as part of a full developmental assessment. Although Lindy Wyman is the teacher working particularly with this family, I helped out with the communication assessment.



THURSDAY

All day with a little boy I have worked with for 2½ years. Now he is in a new special teaching unit, and the class teacher and I planned his daily programme. Great fun. Then home with him to chat with his Mum.

FRIDAY

A day off for me because on . . .

SATURDAY

I was at the Family Centre again for my regular 3-monthly visit from another family. We always meet on Saturdays, because then the girl's father and teacher can come too, as well as the rest of the family.

SUNDAY

I am planning for next week, when I visit families in Essex, Surrey and Hertfordshire.

COMMUNICATION

For the deaf-blind child, communication is taking place throughout the day, in different ways.



Guy is using the resonance board to learn about 'cause and effect'. As Guy bangs his brick, the board resonates and Guy can both hear and feel the results of his action. Guy learns that he can influence what happens around him.



Joe is enjoying two-way games with his parents.

Communication is *fun* for Joe; when he responds, his parents will tickle him. Joe's parents know how important it is for them to respond to all Joe's communications, and they are alert to the signals he gives.



Paul cannot see enough to lipread, but he can see his mother's signs, so she always uses signs as well as speech. They concentrate completely on each other, as she speaks and signs to him, and he signs in reply.

• FAMILY WEEKENDS

There is something special about the Sense Family Weekends, when a family will come to the Centre to stay, bringing with them any other people that are supporting them locally. So much of value can take place. Bronwen Lilly, the newest teacher on Sense's Family Advisory Service team, writes...

"A weekend living together as part of the extended family of a deaf-blind child gives us all *time* – time to get to know each other, time to share feelings, time to work, time to talk and relax, time to laugh and, most important of all, time to become friends."

• THE MANOR HOUSE



The Manor House is situated at Market Deeping near Peterborough. It is a beautiful old house with a range of outbuildings and a large garden.

Opened in 1980, it was the first rehabilitation and training centre in this country for deaf-blind adolescents and young adults.

The 17 students are taught the skills needed to be as independent as possible:

- To use what senses they have to understand the world around them.
- To cope with everyday demands such as using money, travelling, shopping and eating out.
- To use their hands and creative talents in craftwork and hobbies.
- To be able to communicate, using every means, with their fellows, the staff and the world outside.

Most of the students attend Sense workshops at Werrington, five miles

away, travelling there by bus. Here they learn craft skills and are taught the routine of work.

Sense sells their products through its shops and other sales outlets. These are craft goods such as macrame, pottery, jewellery, wooden and printed paper objects.

The students enjoy swimming in their own pool, an environment which is very reassuring to deaf-blind people.

They are well integrated in the local community and join in educational and sporting activities.

Recently the students completed a sponsored walk and raised £300 to buy equipment for the local health centre – a case of 'Do unto others as they do unto you'.

Last year, the second of the Manor House's Group Homes opened in the village, enabling three more students to learn to live more independently.

• CLIMBING MOUNT SNOWDON

Urged on by the promise of tea we neared the summit.

Maurice was struggling now, he wiped his brow and took his own pulse. Then his jersey came off Then it was back on. Then he walked backwards for a while

By now Maurice was decidedly worn out.

which slowed us even more.

He started signing.

Quiet Maurice who doesn't say much started signing.

He was hot.

He was tired.

He had had enough.

He beckoned me down the mountain.

Kanhai wanted to go on and we were so near.

A helicopter flew by and it was below us.

We reached the summit. How exhilarating. We'd done it. I could hardly believe I'd done it myself – let alone Kanhai and Maurice.

I was so proud as people came over and congratulated them. And they were proud of themselves too. Smiles from ear to ear.



IN THE MIDLANDS

COMMUNITY CARE

One of the "buzz-phrases" nowadays is community care. But if a dcaf-blind young adult comes out of hospital, where are the skills and services in the community to allow them to live happily? For some, the answer is to attend a specialist centre such as Sense-in-the-Midlands as a 'stepping stone' to community living. For others, Sense can provide direct advice to local authorities on planning their services.

Last year, Sense advised on the placement and care of several deaf-blind young adults moving into group homes, hostels and 'foster care'.

Last year was a year of growth at Sense-in-the-Midlands.

The five-acre site in Edgbaston – formerly a school for deaf children – is undergoing transformation to become the largest deaf-blind centre in Europe. Builders have been on site, and services have been started, on Sense's biggest-ever development.

The Further Education and Rehabilitation Department offers intensive teaching and sympathetic care to deaf-blind young adults, many of whom have been staying in mental handicap hospitals. After some years at Edgbaston they can hope to live more naturally within the community. The first five students arrived in January 1987. As the building programme completes new family units, each catering for five students, then more will arrive. Staffing levels will be very high, to enable each student to receive individual attention.

The Family Centre, opening in Autumn 1987, will offer support to the many families in the Midlands with young deaf-blind children. It will combine a homely atmosphere where parents can stay with their children, along with well-equipped teaching and activity rooms.

The Conference and Courses Centre has been offering a variety of training opportunities throughout the year. A four-week course for teachers in the summer of 1986 was offered by tutors from Gallaudet College, USA. Many short courses have also been held; for teachers, for care staff, for physiotherapists, psychologists and other groups.

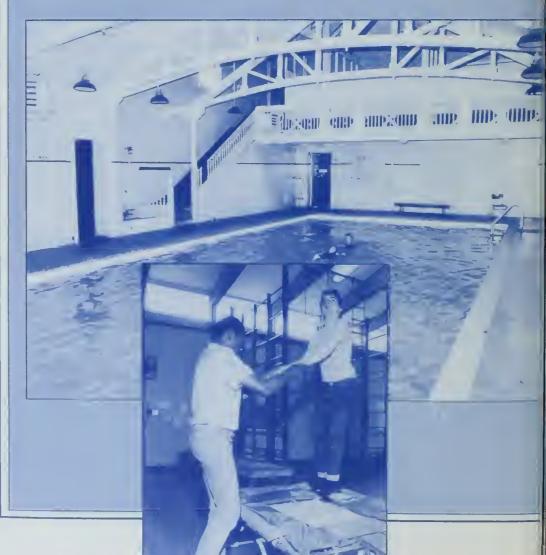
The Support Services Team is beginning to develop, offering support and advice to people working with deaf-blind adults in other locations.



• MAUREEN

Her hairstyle looks good and she knows it!

Maureon is totally deaf and blind. When she arrived at Sense-in-the-Midlands four months ago from a large ward of a mental handicap hospital, her face was scarred from self-inflicted scratches and her frustration showed in every move she made. Now she is starting to communicate again and to rebuild her confidence in herself.



Co operation with other agencies is a theme of our development. On site at present is the Technology Information Centre for the National Deaf Children's Society; the Royal National Institute for the Deaf's Midlands regional offices; the West Midlands Regional Health Authority Support for Hearing-Impaired Adults' project; and students from Queen Alexandra College for the Blind.

Sense-in-the-Midlands has ambitious future plans, including the growth of off-site housing, increased Day Centre facilities, a well-equipped library and improved recreational facilities. An appeal for £2.75m has been launched.



Specialist Gym and Support Team wimming Pool 3 units planned (15 beds) subject to funding 4 units (20 Family beds) — Young Accommodation Adults Other Rehabilitation Course **Organisations** Students Centre (completed Courses and August 1987) Conferences Family Centre 100 Metres 0 80 Edgbaston Ground Plan

• COURSES

There are so many skills that staff should have, to work with deaf-blind ehildren and adults. In schools, hostels and in the home people are crying out for training. Many deaf blind young adults still live in mental handicap hospitals, where low staff levels and lack of specialist knowledge can spell underachievement and frustration.

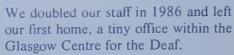
Last year Sense ran courses in 11 hospitals, for a total of over 300 staff. We also staged several 1-day, 2-day and 5-day courses for teachers, eare-staff, families, psychologists

• WEEKEND AWAY

Last year 360 people deseended upon Edgbaston's traditional calm, for Sense's Annual Weekend Away. Children, parents, teachers, social workers – all came together in a unique weekend of sharing. For some, it is a great chance to pick up new ideas and learn. For others, it is a meeting place to see old friends, to break down the isolation that so many people feel. As one parent wrote, "it gives me the strength to earry on a bit longer."



• IN SCOTLAND



We have settled down in more spacious accommodation at Partick Cross, in the centre of Glasgow's West End and convenient for all forms of transport.

It has been a year of progress, of discovering the extent of deaf-blindness in Scotland – previously unquantified, and beginning to plan and develop to take care of the needs we are finding.

Scotland already has a specialised school for deaf-blind children, Carnbooth; Overbridge covers post-school years and a Family Advisory Service will soon be born. This is just the range we are working on – the number of places we shall eventually need is another matter.

And what about provision after Overbridge? Long-term sheltered care according to individual need is a major problem we are looking at closely right now. It will not come into being easily or cheaply but it must be provided.





OINTERNATIONAL WEEK

Last year, Sense-in-Scotland put in a tremendous effort playing host to an Activity Week for young deaf-blind people and their guide/interpreters from all over Europe. 'A Taste of Scotland' was the theme. The variety of activities and the promise of new friendships attracted the largest number of applications ever to such a week. The final count stopped at 68, with groups from Holland, Switzerland, France, Germany, Finland, Ireland and England. What a mixture of personalities, of languages and of communication systems! Each country has its own finger spelling system and their own signs, let alone their own language. Yet we all mixed as one, and the barriers to successful communication crumbled before our determination to get to know each other.

• HOLIDAY

Last year we took six deaf-blind youngsters on our first holiday to Bridge of Weir. An excellent centre for country walks and horse-riding, scarcely less active pursuits were water play and finger-painting.

We also used the holiday to get to know the youngsters and to assess them informally as candidates for places at Overbridge House.

OUR SHOP

Last year we opened our first Scottish Sense Charity Shop here in Glasgow with a professional manageress and a band of enthusiastic volunteers. Things have gone so well that we are already planning to open a second one in 1987.

OVERBRIDGE

Sometimes it can be said that a great undertaking springs largely from the enthusiasm and effort of one person. Sheena Tulloch fought for provision for deafblind school leavers to continue their training in personal and life skills beyond the school years into early adulthood.

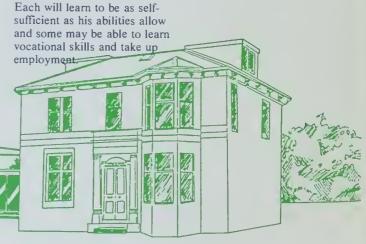
It came into being when Sense, Quarriers, and local and central government got together, the building was offered, the money found and in 1986 the first staff were appointed.

The first six-student unit is now over and cunning; a second similar unit will follow this autumn.

Each young person has individual methods of communication some are extensive some limited.

Similarly each one's degree of sensory impairment, likes and

dislikes, are different. For up to six years each student will therefore pursue an individually designed course – focussing on learning daily living skills, creative work and leisure activities.



• AT THE GRASSROOTS •

Sense Branches are groups of parents, interested professionals and friends who meet and keep in touch with one another and with the main Association, to bring mutual help and benefit at a local level into the lives of deaf-blind ehildren and adults with their families or carers.

Each Branch starts with a small committee but can choose its own way of working and growing. Some see

themselves mainly as family support groups while others have taken on large projects such as eampaigning for local educational provision or actually working towards a group home in their area.

Representatives from each Branch meet together with Sense's Liaison Officer to discuss policy and keep parental involvement high within the Association.



• CARAVANS

Last year Sense Branches, through their own local fund raising, added a sixth family-sized caravan to our holiday resources. These are situated in attractive rural or coastal sites. Although Sense member families naturally have first choice of bookings the caravans are sometimes available for hire by our friends and supporters.

• NORTHERN IRELAND

Last year saw the birth of Sense-Northern Ireland. Our new parents group is already campaigning for schools and services. Is it right, they ask, that families have to travel to Sense's Family Centre in London in order to get the help they so desperately need? "I sometimes get so caught up in my own troubles that everything seems hopeless. At a meeting I get my perspective back and my own problems don't seem impossible any more."

"We do raise some money, but only by doing things that are fun. We have to leave the serious stuff to others who have more time. We could do with some more of those, I suppose."

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PRELUDE

In 1946 Margaret Brock contracted rubella (German Measles) and her son Christopher was born blind and deaf. In 1954 she met Peggy Freeman who had a daughter Bunty aged two, also deaf and blind. Neither had ever seen any other deaf-blind children Because they had so much to talk about and so many problems to share they decided to try to find other families with rubella handicapped children.



• THE EARLY DAYS

They wrote letters and articles to magazines, and the BBC. Their contacts grew and at the end of the year they had found twelve other families. In 1961 they numbered nearly fifty and felt confident enough to name themselves 'The Rubella Group' and became a registered Charity.

In those days they functioned largely on a 'crisis-support' basis, so scattered that their links were the newsletter and their life-lines the telephone. The struggle for suitable specialised educational provision began then – it is still not ended, despite tremendous support from the teaching profession all along the way.

OTHE PRESENT DAY

More than thirty years later Sense, the successor to that 'Rubella Group', is the professionally run organisation whose work forms the substance of this Annual Review. But, 'our roots are our branches'. Our branch network preserves the essence of our early days – parents meeting together, sharing their problems, supporting each other, are still at the heart of our organisation.

MARSHALL

• RUBELLA

Rubella (or German Measles) is a mild infectious disease usually causing a slight rash and a few aches and pains. So what is all the fuss about? If a woman is infected with

If a woman is infected with rubella virus in the first half of her pregnancy there is a serious danger that her baby will suffer damage to its sight, hearing, heart or brain, or any combination of these.

• RUBELLA - THE CAMPAIGN

Under the patronge of the Princess of Wales, the National Rubella Council campaigns for people to gain immunisation against rubella. Even today, when a vaccine is readily available, we still meet many many new rubella handicapped children each year. Last year Sense helped to put the message about rubella onto TV, radio and newspapers.



Four o'clock and Marshall's home from school. He bounces cheerfully into the sitting room where I am chatting with his mother, Gill, and heads for the strong sunlight on the window seat. Suddenly aware of the stranger, he comes swiftly over and gently checks me out, touching the beard and looking closely at my hair and face.

Gill did not know that she had had Rubella during pregnancy, so for Jerry and herself the gradual realization of something wrong with their baby and the unfolding of the truth was very hard to absorb.

Marshall was born severely deaf, with cataracts and a heart defect.

"We first started to suspect that there was something wrong when Marshall was about eight weeks old. The other

babies at the postnatal clinic seemed to be more active. I didn't realise that he had cataracts. Unconsciously I'd compensated and at mealtimes I'd learned to touch Marshall's cheek with his spoon so that he would turn towards the food. He obviously couldn't see it".

We chatted about the early years and Gill recalled the endless visits to hospital, having cataracts removed, hearing and vision assessed and trying different aids. "Later I realised how little time I'd had simply to love and care for him".

Gill remembered lots of the early milestones, not so different from any child growing up, but remembered tenderly because of the hard work Marshall had put in to achieving them. The day he first ate a bag of crisps,

Measles, Mumps & Rubella



• MMR

A new combined vaccine called MMR to protect children against measles, mumps and rubella will soon be offered to infants at 15 months old. This will reinforce the present schoolgirl vaccination programme and take us one step further towards eradicating rubella handicap in children. This scheme will be

available throughout the country in about two years. Sense will be closely involved in the campaigns to ensure that *all* children receive this vaccine. The Rubella Vaccine is one of the safest vaccines in existence. All you will feel is a pin-prick and that's surely worth it for the peace of mind.

his first steps. Indeed Gill recalled how quiekly he became mobile leading to his being found at the top of a 30ft ladder in the barn, quite unafraid. Marshall also got lost one day and was found in the hen house chasing chickens. The flapping of wings, noise, smell and touch would have been exeiting for any two year old, let alone Marshall who relied so heavily on those other senses.

We also talked about all the good times. Gill chatted about the first time the family had gone out in a small fishing boat. "We weren't far out when Marshall started to sign for a 'doctor'. He wanted a doctor right there and then 'now please' as he turned a pale shade of green, signing 'doctor' frantically. Still, he recovered and enjoyed the feel of the fish we eaught flapping about round his feet. He thought it was great fun".

Jerry and Gill have a second child, Melissa, now aged 10. Melissa is very honest about her brother, declaring quite openly how he drives her mad sometimes, fighting, teasing and taking her books. Still, Jerry and Gill reckon this is all a fairly natural relationship between brother and sister and really Mel loves her brother a great deal.

"Marshall is twelve now" his mother continued, "I'm constantly under-estimating him and not really letting him grow up. He's been at Cambooth House School in Glasgow since he was five. He's learned to sign, which made a big difference. Now that he can communicate better his frustrations are less. When I tell him to have a bath, he can tell me to get lost — a perfectly able boy!

"I'm trying to learn to treat

vaccination last?

Marshall as a young man, to let some of the strings go, to let him take some risks, have choices and take opportunities. We hoped he would learn to talk and be able to get sheltered work. Maybe he will, maybe he won't, but what is important is that we respect him for what he is. Within his own limits our son is able, good company with an extremely developed sense of humour. He knows exactly what he wants and more importantly how to get it".

"In the end we want Marshie to live as full a life as possible. He shouldn't live with us but be as independent as he can. So we hope that he can leave home and go to a good placement, developing at his own pace with people who know and care for him.

"Our greatest fear is what will happen when we are no longer here. It is so important that Mel feels in no way responsible for Marshall after we are gone. Still in many ways it is down to Marshall - given how hard he fights to do things, we are all sure he will come through able to take care of himself and, more importantly, to be

Meanwhile Marshall has returned to his window and continues to watch the sunlight.



RUBELLA **FIELDWORKERS** Sense's Rubella Fieldworkers go

out into the community to increase the number of women and girls who are vaccinated against rubella. Liaising closely with health authorities they publicise the danger of rubella to the foetus of a pregnant woman. In schools they may show Sense videos to the children, check vaccination records and try to improve the 'uptake rate' to as near 100% as possible.

• VIDEOS

Sense's video's carry the message that immunisation against Rubella is vitally important. Three such videos, "Go for it", "Why worry" and "Rubella" aimed at schoolgirls, women of child-bearing age and Asian Women (with dialogue in Hindi and Bengali) are now available.

READ THIS LEAFLET **BEFORE** YOU GET **PREGNANT**

mild disease, why

Sense produces information material as a contribution towards the National Rubella Campaign

When is the best time to be vaccinated? Is the vaccine How long does the

harmful? Will it hurt? How do I make sure I'm protected agains What is Rubella? rubella?

If rubella is su.

so dangerous?

I've already ho Am Limmorell

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(WW)

• FINANCIAL REPORT Anyone reading Sense's accounts for the year ending 31 March 1987 will find not one, but two sets. Our major area of expansion has been on the site of Sense-in-the-Midlands which is still formally administered by a separate charitable trust, currently called the Royal School for Deaf Children, which was the former title of the establishment. The summaries of income and expenditure given on this page relate to both sets of accounts and as such provide a faithful reflection on all our work during the year. Substantial developments in our Rehabilitation and Training Services are already showing in these accounts since the first six students at Sense-in-the-Midlands began to arrive during the final quarter of that year. Regular recipients of this report will be aware, not only of how much extra has been carried out this year, in financial terms, but also how thoughtful we need to be before we commit ourselves to heavy expenditure. We are not yet so well established that we can confidently predict our legacy and appeals income. We must therefore continually review our activities and decide what we can afford and what must wait. None of the income that we have been able to raise has come easily, especially since the demands on voluntary and charitable services grow ever more intense each year. We have yet to find a way of describing the real efforts that have gone into our achievements - so far we have only been able to quantify them in terms of money how much we received and spent, where it came from and where it went. This does not take into account the enormous resource of unpaid help and support we have received, and we estimate that, if quantified in financial terms, it would more than double the figures shown. Our thanks are therefore due to all the Sense members, employees and volunteers who worked so hard during the year to enable us to take the brave steps we have taken in our aims of meeting more of the needs of deaf-blind and rubella handicapped children

Rodney Clark Director On behalf of Sense's Council of Management

and adults and their families.



FINANCES •

TOTAL INCOME £1,486,271

Legacies £101,549 (7%)



Interest, Special Events and Sundry Income £195,823 (13%)

Manpower Services Commission £187,862 (13%)



DHSS, Local Authority £256,821 (17%)

Donations and **Subscriptions** £457,905 (31%)



Fees for Residential Services £286,311 (19%)

TOTAL EXPENDITURE £1,453,440

Education £204,486 (14%)



Family Support & Welfare £236,711 (16%)

Fundraising £110,588 (8%)



Rehabilitation and Training £551,687 (38%)

Information and Awareness



Administration £89,884 (7%)



Copies of the audited Final Accounts for both Sense and Sense-in-the-Midlands may be obtained from 311 Gray's Inn Road, London WC1X 8PT



• THE NEXT STEPS

Sense is poised to take the next steps. Plans are being laid for future prospects all that is needed is the support to carry them out.

Young Children

Our Family Advisory Service needs three more teachers, to cope with the ever-increasing referrals.

School Children

We need to establish a Teacher Training Course; we must expand our Holidays programme, so that we no longer turn children away.

Young Adults

We must complete the building work at Sense-in-the-Midlands to give places for more students, to upgrade

the swimming pool and gym, and to

- the Manor House needs to open a hostel to offer long-term care for its less-able students
- —we need to build up our Support Services Team, to help deaf-blind people wherever they live

Families

—to improve our support for individual families around the country, we need to appoint Regional Officers.

offer long-term care in the community.

NOW IT'S YOUR TURN

To continue and develop our work Sense needs:-

Your thoughts

Will you remember us in your will? Buy cards or presents from our Christmas catalogue? Support Sense shops? Publicise Sense's work wherever you can?

Your donation

However small a gift will help us to help a deaf-blind child. A covenant will make a donation worth much more, as we can reclaim income tax, at no extra cost to you. Through Give-As-You-Earn at work, make Sense your chosen charity.

Please contact Ian Wratislaw, Head of Appeals, if you want to help.

• Your time

Be a Sense volunteer, help with our holidays, or in a shop. Join a Sense branch: become

a member of Sense.

O"I LOVE HIM AND HE'S GOING TO LIVE"

Twenty four hours after Joe birth, I overheard two mothers whispering that there was 'something wrong with one of the babies born yesterday'. I tried to convince myself that they were talking about another ehild - but I knew they meant mine. When I was told not to get too fond of him because he was not going to live, my brain silently answered 'too late, I love him and he is going to live'. My health visitor told me she

had never seen a ehild like Joe, could not really give me any advice and rarely eame. Nor did anvone else! I do not know who eried most, Joe or me. We rarely went out except for hospital visits which were, from our point of view, useless. The paediatrieian was determined to find a label to pin on Joe and finally settled for 'GOK' which, he explained wryly, meant 'God only knows We did not need a label. What we did need was eonstructive advice and help. I heard about Sense. Their Family Centre approach was that Joe was like any other baby to be eooed at and played with. He was not being prodded about, tested or examined, it was almost a revelation that someone else saw our baby as a baby! The Family Centre were indifferent to a label but offered practical help for work and play. The time we all spend at the

Family Centre seems to fly by, and the visits to our home

by Christine Laffan, Sense's

advisory teacher, are



